

PARTICIPANT INFORMATION SHEET FOR ELDERLY MINORITIES AND THEIR FAMILIES

Developing a resource to support BAME communities through the COVID-19 epidemic

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

Evidence suggests that COVID-19 has unequal impact in ethnic minority groups. Higher hospital admission and death rates from COVID-19 have been seen in ethnic minority groups compared to people from white ethnic background in the UK. Elderly ethnic minorities are particularly at risk of poor health outcomes from COVID-19 due to age-related health risks. Effective communication of health information is important to improve health outcomes, but this is challenging in elderly minority groups due to language barriers and cultural differences.

We aim to work together with elderly ethnic minorities and their families to develop health education materials on COVID-19 that are appropriate to their culture and language. The project will mainly focus on Indian and Nepalese communities in Kent, Surrey and Sussex to identify their health information needs on COVID-19 and work together with these communities to develop health education resources. Once we develop the resources, we plan to implement these resources working together with community organisations, local authorities and other relevant bodies.

The study will run for a total of six months and we hope to interview elderly minorities, their families and healthcare professionals.

Why have I been invited to participate?

You have been invited as you are from an Indian or Nepalese background and therefore within the minority ethnic community. We believe that your insights will be valuable to address the information needs of the minority communities. We are aiming to interview around 12 elderly minorities and 8 family members for this project.

Do I have to take part?

It is completely up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to verbally consent (which will be recorded) to be a part of the study. If you decide to take part, you are still free to withdraw from participation at any time and without giving a reason. If you want to withdraw your data from the study you will have two weeks (after the interview has been conducted), after which it will no longer be possible to withdraw data.

What will happen to me if I take part?

If you wish to take part, the researcher will arrange a time which is convenient for you to conduct the phone/ online interview. You will be given the opportunity to ask any questions prior to the interview, and during the call. The interview will last approximately 1 hour and will give you the opportunity to share your experiences of your health information needs regarding COVID-19.

In addition to the interview, we will request some of you to be involved in the co-production process in order to design and develop health education materials. You will attend regular meetings (around three meetings) over a 6-month project period. In the meetings, ideas will be discussed on the content and format of the health education materials.

What are the possible risks and benefits of taking part?

Your feedback provides valuable information for the service and we hope that the findings from this consultation will be used by local authorities and the NHS to improve service for BAME communities. Although we will not be specifically

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asking about past experiences of poor health implications, it is possible that some conversation topics around COVID-19 and associated health messages might produce feelings that could be distressing to participants.

Will my information in this study be kept confidential?

All participant information will be kept anonymous and data collected will be stored in accordance with the General Data Protection Regulation (GDPR) 2018. The researchers will adhere to the requirements of the University of Sussex's Research Data Management Policy. A unique study identifier (participant number) will be allocated to each participant at the time of consent.

Interview recordings will be transferred from the digital recording device to a password protected computer and recordings will be destroyed straight after transcription. No one will be given access to the information collected except for the researchers.

What should I do if I want to take part?

Taking part is entirely voluntary. You can withdraw from participating at any time without needing to give an explanation, and without bias or consequence. If you do wish to take part, you can contact the researcher (contact details below) and they will arrange a time to call you for the phone/ online interview.

What will happen to the results of the research study?

All outputs from this study will be anonymised. You will be offered a summary of the report. The findings will be submitted for national and international conferences and any further suitable events. The results of the study will be written up and published in a scientific journal.

The information resources developed from this study will be distributed using the network of community organisations, local authorities and other channels (for e.g. social media, local newspapers and radio stations).

Who is organising and funding the research?

The research is funded by the National Institute for Health Research Academic Research Collaboration Kent Surrey and Sussex (NIHR ARC KSS), and is being conducted by the Brighton and Sussex Medical School (BSMS), in collaboration with University of Sussex, Brighton and Sussex University Hospital Trust, and University of Surrey.

Who has approved this study?

The research has been approved by the University of Sussex Research Governance Office and the ethical review application number of the study is: ER/BSMS3653/6

Insurance

The University of Sussex has insurance in place to cover its legal liabilities in respect of this study.

Contact for further information

For any further information you can contact the research team on the contact details below:

Principal investigator: Dr Priya Paudyal, Tel. 07896182850 or email: p.paudyal@bsms.ac.uk

Project Research Fellow: Name: Saliha Majeed-Hajaj, email: s.majeed@bsms.ac.uk

If you have any concerns about the way in which the study has been conducted, you should contact the University of Sussex Research Governance Office who reviewed the project (for staff research). Their contact details are:

E: rgoffice@sussex.ac.uk

Thank you for the time you have taken to read this information sheet.